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Toward dignity-centred ethics in the treatment of longstanding and severe eating disorders: a lived experience-led narrative review

James Downs[1,*], Marissa Adams[2]

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Abstract

Longstanding and severe eating disorders (LSEDs) are frequently marked by medical risk, therapeutic impasse, and exclusion from standard care pathways. Yet insufficient attention has been paid to the ethical dimensions of treatment for those with complex and longstanding illness trajectories, in particular from the perspective of those with lived experience. This paper aims to address this gap as a lived-experience-authored narrative review focused on the concept of dignity as a guiding value of ethical care in LSEDs. Informed by critical interpretive synthesis, narrative ethics, and reflective practice methods, the authors integrate multiple sources of evidence. They adopt a lens of epistemic injustice, situating subjective knowledge alongside empirical research findings and the wider conceptual and ethical considerations of treatment provision. The findings identify recurring patterns of undignified care in the treatment of LSEDs, including the normalisation of neglect, coercive practices, and exclusionary models of treatment. Principles and practical steps are outlined to inform dignity-affirming care, which include prioritising relational safety, co-produced decision-making, and re-medicalisation of LSEDs in ways that do not sacrifice autonomy. Ultimately, the authors determine that a dignity-centred approach to LSEDs requires a fundamental shift in how we understand risk, chronicity, and the place of lived experience in clinical ethics. This paper offers a conceptual and methodological framework to support that shift, calling for collective responsibility and structurally embedded forms of care that respect the knowledge, rights, and needs of those most affected by LSEDs.

Keywords: *compulsory treatment, involuntary treatment, eating disorders, dignity, autonomy, lived experience, anorexia nervosa, coercion and autonomy, ethics*

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1. Introduction

While contemporary mental health discourse increasingly recognises dignity as central to care, individuals with longstanding and severe eating disorders (LSEDs) often confront systemic barriers to accessing care that undermine their humanity [1, 2]. Barriers to treatment include (but are not limited to) the misrecognition of medical risk [3, 4]; the minimisation of patient suffering [5]; and care models that frame illness as intractable and beyond the remit of intensive intervention [6–8]. All these exist within healthcare contexts, whereby specialised ED treatment is often starved of sufficient resources to meet the demand for treatment [9]; clinicians, including medics, often lack training [10]; and EDs are seen as a niche, specialised area [11].

As people who have lived with LSEDs, we have experienced the consequences of these structural problems in the context of our daily lives, where the possibility of suffering, seeking treatment, and recovering with dignity has often felt elusive. Interactions with services have, at times, stripped us of a sense of self, particularly when decisions were made without our involvement, or when our bodies have been assessed but our unique identities and personhood have been overlooked. Yet we have also experienced the transformative power of care that centres dignity, even under constrained circumstances.

This paper draws on personal experiences, theory, and empirical research to critically examine how dignity can be both conceptualised and operationalised in the context of LSEDs. We take a particular focus on the paradox of demedicalisation and the role of coercion in care, seeking to challenge the stigma that often surrounds individuals with LSEDs and emphasising the need for co-production across research, policy, and practice. In itself, this work is an attempt towards ensuring that the voices and experiences of those living with LSEDs are heard, respected, and integrated into the care models designed to help them [12–14]. We hope this will pave the way for more compassionate, effective, and dignity-centred care, recognising individuals not just as patients but as people deserving of respect, autonomy, and agency that extend beyond their treatment into the rest of their lives.

2. Materials and methods

This paper adopts a narrative review methodology, drawing on the interdisciplinary literature, lived experience, and critical ethical inquiry. Our aim is not to generate generalisable findings but to advance a situated and theoretically grounded understanding of dignity in the context of LSEDs. The approach is informed by

[1]Independent Researcher, Cardiff, Wales, UK.
[2]Independent Researcher, Nashville, TN, USA.
*email: jamesldowns@gmail.com

critical interpretive synthesis (CIS) [15], which supports conceptual innovation by integrating insights across diverse sources and privileging depth of understanding over systematic coverage. CIS is particularly appropriate for interrogating complex, value-laden concepts such as dignity and allows for iterative, theory-informed engagement with the literature, policy, and experience [16]. We (the authors) write from a position of dual expertise—as individuals with personal experience of living with LSEDs and as researchers engaged in advocacy, consultation, and collaborative scholarship within the field of EDs. Our positionality is thus both experiential and analytical. While no formal qualitative data were collected, we used methods adapted from reflective, participatory inquiry to inform our reflexive experiential analysis (i.e., to write in light of the knowledge gained by subjective experience) [17, 18]. This included generating priorities based on experiential material, joint reflective analysis discussions, and iterative rewriting—all in relation to the existing academic literature. In this sense, this paper reflects a fusion of horizons between lived experience and ethical theory.

A central epistemological commitment in this paper is to the concept of epistemic injustice, first developed by Miranda Fricker [12]. Epistemic injustice refers to how individuals or groups are systematically discredited or excluded from knowledge production, whether through testimonial injustice (being disbelieved or dismissed due to identity-based bias) or hermeneutical injustice (lacking the interpretive resources to make sense of one's experiences within dominant frameworks) [19–22]. Within psychiatry and ED services, these dynamics manifest when patients' insights are marginalised, rendered unintelligible, or superseded by alternative, often inaccurate or stigmatising, explanations within treatment settings and wider clinical and academic discourse [23, 24]. We apply the lens of epistemic injustice to argue that experiential accounts are essential for greater equity and epistemological completeness in discussing the ethics of treatment for LSEDs [14]. Throughout this paper, we use the concept of epistemic justice both descriptively, to identify exclusionary patterns in care, and normatively, to inform recommendations for dignity-affirming practice.

The primary sources for this paper include

- Conceptual engagement with key constructs including dignity, autonomy, coercion, demedicalisation, and relational care;
- A purposive review of the literature across clinical ethics, mental health policy, communitarian theory, medical sociology, and eating disorder (ED) scholarship;
- Analysis of reflexive narratives, developed through structured dialogue between the authors over several months.

We intentionally frame this as a narrative review rather than a systematic review, given the conceptual and exploratory nature of our analysis. The literature reviewed was selected purposively and iteratively through database searches (e.g., Google Scholar, PubMed), known networks of scholarship, and key reference lists, using terms such as "dignity in mental health", "severe and enduring eating disorders", "coercion in psychiatry", "epistemic injustice", and "trauma-informed care". Searches were conducted and refined between March and July 2025 in parallel with the development of the conceptual framework.

Approximately 400 potentially-relevant sources were initially identified across published academic articles and book chapters. Following title and abstract review, we selected sources that directly informed our analysis of ethical care in the context of longstanding and severe eating disorders. These were integrated into the manuscript alongside a smaller number of additional references related to methodology, conceptual framing, and healthcare policy, totalling 222 sources overall. Inclusion was based on relevance to our guiding concepts (e.g., dignity, coercion, epistemic justice), resonance with lived experience themes, and influence within clinical, policy, or ethical discourse. We deliberately prioritised lived-experience-led, co-produced, and equity-focused contributions, including commentary and reflective scholarship alongside peer-reviewed articles, in line with our epistemological commitments. Sources that did not substantively engage with ethical dimensions of care, or that focused solely on acute/early-stage illness, were excluded. This flexible, iterative approach reflects the principles of critical interpretive synthesis, which emphasises conceptual innovation, inclusivity, and the integration of diverse forms of knowledge over comprehensive or reproducible coverage [15].

Our interpretive framework has also been informed by decolonial and epistemologies that reject oppressive hierarchies in knowledge production [25–29]. This includes an explicit commitment to addressing the historical marginalisation of patient voices in psychiatric discourse by centring relationality, justice, and accountability in mental health research [30–32].

We recognise the limitations of this approach, particularly its situated nature and non-generalisability. However, we argue that narrative, reflective, and participatory methodologies offer critical insights often overlooked in purely clinical or policy-led analyses, especially in contexts where service users have been structurally excluded or pathologised.

3. Results

3.1. Conceptual findings

3.1.1. Multiple perspectives on the nature of dignity

Dignity is a complex and multifaceted concept, with diverse interpretations shaped by philosophical, cultural, and clinical perspectives. Philosophically, Kantian approaches ground dignity in the inherent worth of individuals, asserting that every person, as an autonomous agent, possesses an intrinsic right to respect due to their capacity for rational decision-making [33]. In contrast, contemporary rights-based perspectives, as enshrined in international human rights law such as the Universal Declaration of Human Rights from 1948, posit that all individuals are entitled to live free from discrimination and with equal access to the resources necessary for well-being. This view aligns with the idea that dignity cannot be separated from the rights to health, freedom of expression, and participation in societal processes. It serves as the foundation for the notion of equality, where each person is treated with inherent respect and their rights are actively protected.

Communitarian approaches, on the other hand, understand dignity in terms of relational values, highlighting the importance of community, social ties, and collective well-being [34]. Communit-

arians argue that a person's dignity is preserved when they contribute to the community and when the community upholds shared ethical norms. In healthcare, this can mean that dignity is preserved not only through individual rights but also through collective support systems and social structures that ensure care is provided in ways that respect the interconnectedness of people [35–37]. An ecological perspective is also relevant, as it considers the broader environmental and systemic factors that influence a person's well-being and recovery [38, 39]. A dignity-centred approach informed by ecological principles would take into account these wider determinants, advocating for interventions that address not only immediate clinical needs but also the broader social and physical environments in which individuals recover.

These perspectives—Kantian, rights-based, ecological, and communitarian—are just a few of the many ways dignity has been conceptualised. While there are other frameworks and cultural understandings that further enrich the discourse on dignity, this paper focuses specifically on rights-based and communitarian perspectives and the insights they offer for upholding dignity in healthcare, particularly in the care of people living with LSEDs.

3.1.2. Conceptualising longstanding and severe eating disorders

While the terms "severe and enduring eating disorder" (SEED) and "severe and enduring anorexia nervosa" (SE-AN) are frequently used in research and clinical practice, their definitions and operationalisation remain inconsistent and contested [40, 41]. A review by Birch et al. [42] illustrated how across 11 studies, the definitions of SEED and SE-AN varied considerably, with illness duration thresholds ranging from three to over forty years and unclear or inconsistent criteria for severity. Others have argued that functional impairment, quality of life, and unsuccessful treatment attempts may offer more meaningful indicators of severity than duration alone [43–45].

Critics have also raised ethical and clinical concerns about the term "SEED". Whilst some patients have described the term as validating the seriousness of their condition [46, 47], others have argued that the term "enduring" in particular may inadvertently promote therapeutic nihilism, reinforce clinician pessimism, and undermine the possibility of meaningful recovery [48–50]. By appearing to situate the difficulties of treatment within the nature of illness itself, the "SEED" term may also obscure the structural and systemic factors that contribute to poor treatment outcomes, including exclusionary referral criteria, a lack of tailored interventions, and widespread resource constraints [2, 8, 9, 42, 51–54].

A recent qualitative study of patient views by Lubieniecki et al. [55] captured the contradictory nature of "SEED", questioning whether it operates as "a lifeline or a label" and illustrating how diagnostic language shapes access to care, clinician attitudes, and personal identity. Together, these ongoing debates point to the difficulty of constructing a diagnostic entity based on chronicity, in the absence of a clear empirical or nosological consensus. Importantly, diagnostic manuals do not include "enduring" or "chronic" variants of EDs as formal diagnostic categories [42, 51].

In this paper, we use the term "longstanding and severe eating disorders" (LSEDs) as a descriptive umbrella, rather than a diagnostic label. We define LSEDs as EDs characterised by persistent psychological and behavioural symptoms, significant medical instability or risk, social and functional impairment, and histories of a limited response to conventional treatment. Many individuals with LSEDs have cycled through multiple inpatient or outpatient treatment episodes without sustained improvement, often encountering exclusionary service criteria or stigma related to being perceived as "non-recovering" or "treatment-resistant" [2, 8, 49, 50, 56, 57]. Our framing intentionally avoids implying permanence, irreversibility, or failure and instead invites critical reflection on how diagnostic language can shape access to care, therapeutic possibilities, and the ethical climate of services.

Despite the conceptual ambiguity, we acknowledge the reality of medical instability, suicidality, co-occurring conditions, and multi-organ complications amongst those with LSEDs [58–62], with high levels of preventable ED deaths reported across multiple studies and service reviews [3, 52, 63–66]. High levels of clinical need and risk mean that individuals with LSEDs often require repeated inpatient admissions or prolonged engagement with health and social care systems. These features also raise complex ethical questions regarding treatment decision-making, particularly in relation to compulsory treatment for those with LSEDs [67, 68]. This is discussed in more detail later, where we consider how the conceptual lens of dignity can inform practical caregiving in the context of compulsory treatment, helping to navigate the balance between the preservation of life and respect for autonomy, agency, and individuality.

3.1.3. Conceptualising dignity as a process and an outcome

Recent research by Klinner et al. [69] shows how dignity can be conceptualised in multiple, interrelated ways—including respect, safety, belonging, equality, and professionalism—across different professional roles in healthcare. Their findings portray dignity not as a singular or static concept but as a construct that is formed relationally and shaped by institutional, cultural, and interpersonal contexts. Crucially, they identify tensions between dignity as professionalism and dignity as equality, indicating that meaningful efforts to uphold dignity require more than individual goodwill or vague appeals to respect. Instead, they suggest that dignity must be actively cultivated through both relational practices and systemic supports.

This multidimensional and situated understanding provides a rationale for conceptualising dignity in healthcare as both a process and an outcome. As a process, dignity is enacted through everyday clinical interactions that affirm personhood, protect agency, and foster trust. As an outcome, it is safeguarded through structural mechanisms, such as ethical standards, legal protections, and institutional practices, that promote fairness, participation, and accountability. These dual dimensions echo communitarian and ecological theories of dignity [35–39], which emphasise that dignity emerges not only from moment-to-moment care but also from the broader systems and relationships in which care takes place. This framing underpins our later discussion of how dignity operates both relationally and structurally in the context of the treatment of LSEDs.

3.1.4. Cross-cultural and intersectional dimensions

There is a growing body of evidence emphasising the need to account for a range of intersectional factors when considering

how dignity can best be supported in clinical settings for those with LSEDs [70]. Research has demonstrated that race, cultural background, sex and gender, socioeconomic status, and sexual orientation—amongst other determinants—all shape predisposing risk of developing an ED, the symptoms that people may experience, and how individuals access and participate in treatment [71–74]. However, the research to date has largely been confined to narrow demographic groups which do not represent the heterogeneity of EDs and those who experience them [75–77].

For example, a patient from a marginalised ethnic background may experience dissonance between the treatment models provided in Western, individualistic healthcare settings and their own cultural values, which may be more collectivist in nature [78, 79]. In such situations, the rights-based emphasis on autonomy might conflict with cultural expectations that emphasise community or familial involvement in decision-making. If the treatment plan is imposed without cultural sensitivity or consultation with family members, the patient may feel their dignity is disregarded. This highlights the importance of adapting clinical care to respect cultural norms while maintaining the patient's autonomy and rights.

Similarly, socioeconomic factors can significantly affect the perception and enactment of dignity in care. Contrary to stereotypical perceptions of EDs as diseases of affluence, patients from lower-income backgrounds and those without access to medical insurance may face increased predisposing risk alongside greater barriers to accessing ED treatment [80–82]. Whilst a rights-based framework insists that all individuals should have equal access to care, structural inequalities—such as financial hardship, geographical disparities, and inadequate service provision—can create profound disparities in who is able to seek and receive support. Without addressing these material inequalities, the patient's dignity may be compromised by systemic injustices. Here, the communitarian approach can further enrich clinical care by emphasising collective responsibility, ensuring that healthcare systems work not just to serve individuals but to strengthen the social structures that support the most vulnerable.

Another area that resonates with our personal experiences is the intersection of EDs and neurodivergent conditions such as autism [83, 84]. Despite increasing empirical evidence to show that EDs significantly co-occur with autism [85, 86], many autistic individuals remain undiagnosed or misdiagnosed within ED services, leading to treatment delays, and ineffective—or even harmful—treatment approaches [87]. A lack of professional training [88] combined with difficulty discriminating between autistic traits and restrictive ED symptoms [89, 90], can lead to a lack of recognition of neurodivergent needs, exacerbating distress and prolonging illness trajectories [91]. A rights-based perspective may emphasise the importance of valuing autistic differences (for example, in communication, sensory processing, and eating behaviours) rather than pathologising or seeking to "fix" them. Instead, a dignified approach to treatment ensures that recovery does not require conformity to neurotypical norms but is tailored to the individual's needs and preferences [92–94].

From a communitarian standpoint, the social model of disability is particularly relevant, arguing that disability arises not solely from an individual's impairments but from societal structures that fail to accommodate their differences [95, 96]. In the context of ED treatment, this means recognising that many standard approaches—such as group therapy, exposure to social eating, or rigid meal plans—may be distressing or inaccessible for autistic individuals if they do not account for sensory sensitivities, communication preferences, or the need for predictability and routine [97]. A communitarian approach would shift responsibility towards healthcare systems and service providers to create truly inclusive environments, rather than placing the burden on individuals and their caregivers to adapt to a system they experience as not designed for them [98].

A recent case report by Downs & Kelly [99] illustrates the clinical and ethical consequences of failing to fully consider intersectional factors in LSED care. It describes a male patient with a longstanding restrictive eating disorder who died from medical complications, including aspiration pneumonia and gastroparesis. Despite repeated reports of gastrointestinal distress and neurodivergent traits, gastroparesis was only diagnosed postmortem. Their analysis highlights the importance of gender-sensitive care, integrated physical and psychological assessment, and greater attention to epistemic justice in ED care, particularly where lived experience accounts are disbelieved, pathologised, or dismissed. Men with EDs, for example, frequently experience diagnostic delay and misrecognition, with symptoms that fall outside stereotypical profiles often going unacknowledged and clinicians feeling ill equipped to support men's concerns [100–102]. In this context, a commitment to dignity requires not only respect for patient agency but a re-evaluation of whose knowledge is valued and how that knowledge shapes clinical priorities, diagnostic reasoning, and care decisions.

3.2. Reflexive findings from lived experience

Drawing on our own experiences of living with LSEDs and receiving treatment in a range of settings, we have together identified several practices that have compromised our dignity. Whilst these are based on our specific personal contexts and clinical histories, there is evidence to suggest that the following phenomena may contribute more broadly towards undignified experiences of care.

3.2.1. The paradox of demedicalisation

Throughout our illnesses, we have each found that accessing medical care became more difficult at times when we needed it most. Despite the increasing complexity of our physical health problems, marked by severe malnutrition, cardiac instability, and other life-threatening complications, there were many instances where our needs for medical intervention were downplayed or deferred. In some cases, we were told that our co-occurring medical conditions were "psychosomatic" rather than medical emergencies, resulting in dangerous delays in accessing appropriate treatment.

At other times, our ED struggles were minimised or entirely misunderstood, particularly by clinicians without specialist experience. When we sought comprehensive support for escalating medical and psychiatric distress, we were often offered only harm reduction strategies, or no treatment at all, as though intensive intervention was no longer considered appropriate. These responses lowered the bar for what recovery could mean, despite how unwell we were. Even when life-saving measures were eventually taken, decisions were often made swiftly, with little explanation or collaboration. Instead of feeling safeguarded, we were left disempowered and silenced at precisely the moment when meaningful dialogue and compassion were most needed.

We have come to understand these experiences as illustrating what we term the 'paradox of demedicalisation': a shift in some contexts where treatment for conditions such as EDs—long recognised as requiring intensive medical care—is increasingly reframed through primarily psychological, harm-reductive, or even palliative lenses. The paradox lies in the fact that as our illnesses have become more medically compromising and life-limiting, the likelihood of receiving robust medical care has often diminished.

The movement away from over-medicalisation and coercion in mental healthcare can be seen as a positive corrective, particularly when promoting trauma-informed, autonomy-respecting, or community-based approaches. However, evidence suggests that its unintended consequence in LSEDs may be the quiet erosion of medical responsibility. Birch et al. (2024) note that while harm reduction may offer compassionate alternatives to force or exclusion, it should not become a "final destination" in place of medical restoration [42]. Others have warned that applying palliative care frameworks prematurely or uncritically in AN risks therapeutic nihilism, especially in the absence of robust evidence [6, 8]. Importantly, the trend towards prioritising psychosocial care risks displacing medical care and creating a bifurcated model of treatment, where people with acute, early-stage presentations may be fast-tracked for comprehensive intervention, while those perceived as having chronic, complex, or less "treatable" forms of EDs are shifted onto harm-reductive or palliative pathways [103].

This pattern is borne out in clinical data. Studies show that the discharge body mass indices (BMIs) for individuals with longstanding and severe anorexia nervosa (LS-AN) frequently remain below healthy thresholds [104, 105], even after what is classified as intensive treatment. This is concerning given that full weight restoration is a key factor in recovery and long-term prognosis [106–108]. In some inpatient services, the average discharge BMIs for people with LS-AN fall below 17 kg/m^2 [104, 109], reflecting what may be a system-wide shift towards lower expectations of improvement. By contrast, individuals presenting with shorter durations of untreated eating disorders (DUEDs) are often prioritised for assertive, early-stage intervention, including full medical stabilisation [110]. This is despite severity and duration of illness being poor predictors of recovery outcomes [106, 111].

While such disparities may reflect a desire to use resources efficiently or avoid coercion in high-risk cases, they also expose a troubling hierarchy: those with the most complex and enduring illness presentations are often offered the least structured support. In our view, and in line with more detailed critiques of this model [50, 104], the paradox of demedicalisation reinforces inequities in care, where recovery-oriented treatment is allocated based not on need but on assumptions of likelihood, responsiveness, or compliance.

Compounding this, co-occurring conditions, such as autism, trauma-related disorders, and complex physical health needs, may be overlooked or dismissed, particularly in individuals with longstanding EDs [4, 58]. This leads to missed opportunities for integrated care and more personalised treatment planning, which are key to improving outcomes [106, 112]. In our personal experiences, our neurodivergence or comorbidities were sometimes pathologised as barriers to engagement, rather than being seen as factors requiring clinical adaptation [83, 112].

We are not arguing for a return to reductionist or purely biomedical frameworks. But we do believe that when medical care is deemphasised or withheld, it compromises both dignity and safety. For those with LSEDs, the challenge is not simply to humanise care but to remedicalise it responsibly, ensuring that autonomy, compassion, and physical health are held together in ethical tension, not traded off against one another.

3.2.2. The impacts of normalised neglect

A key consequence of demedicalisation in the context of LSEDs is what we term the 'normalisation of neglect': a process by which exclusion from care becomes systemic, routine, and ethically unchallenged. Our own histories reflect this pattern. We define normalised neglect as the cumulative process through which the unmet needs of people with LSEDs are rendered invisible or accepted as inevitable within services. Despite the severity of our illnesses—marked by persistent psychological distress, physical risk, and profound functional impairment—there were extended periods in which we were excluded from care altogether. This was not due to a lack of need or help-seeking but rather reflected organisational norms that increasingly accommodated our exclusion as routine. Over time, this reclassification of need as non-urgent or non-treatable became embedded into our care.

The impacts of neglect are multifaceted. At an existential level, prolonged exclusion increases the risk of deterioration and death, including from preventable causes [52, 63–65]. In our experience, the psychological impacts of neglect have also been profound. We both internalised the denial of care as a reflection of who we were and our value as people, coming to see ourselves as undeserving, beyond help, or not "ill enough" to be taken seriously. The implicit messages we absorbed from being excluded from treatment or having our illnesses minimised only deepened our reliance on disordered eating behaviours for control and meaning and reinforced the sense that our suffering was either self-inflicted or fundamentally illegible to others, decreasing the motivation to seek help. We understand these internalisations not as irrational distortions but as emotionally coherent responses to a system that repeatedly failed to respond sufficiently to our illnesses. They are experiences that are mirrored in multiple types of published evidence regarding the impact of stigma and discrimination in relation to EDs [113–117].

From an ethical standpoint, our experiences were more than individual hardships—they reflect a broader failure of relational justice. In this context, dignity in care involves being recognised as someone whose needs, perspectives, and suffering warrant a meaningful response and should not be contingent on prognosis, perceived compliance, or institutional convenience. Our experiences also speak to the hermeneutic and testimonial aspects of epistemic justice, as our accounts and interpretations of our experience were systematically dismissed or devalued alongside our views about the kind of care we needed [12, 19–24]. This points to the central role of language in dignified care.

3.2.3. The role of language and illness narratives in upholding undignified practices

The language used in clinical settings does not merely describe experience—it helps constitute it and can constrain what is deemed possible within treatment [57, 118–120]. This has borne out in our personal experiences of LSEDs, where the language we have encountered has shaped how we have been perceived, how

care has been offered or withheld, and whether we have felt seen as full persons. Labels such as "high-risk", "non-compliant", "lacking insight", or "beyond treatment" appeared in our documentation and discussions with professionals across services, but rather than reflecting the complexity of our distress, we felt these phrases positioned us as difficult, intractable, or undeserving of help.

In epistemic terms, these examples illustrate testimonial justice [21–23], where the credibility of our accounts was routinely diminished in favour of clinical judgement, giving rise to instances of other health needs and diagnoses being overlooked [24, 58, 83, 112]. When system-generated narratives about "treatment resistance" were given priority over our self-articulated needs, we were rendered narratively silent within our care. In parallel, the absence of relational or structural interpretive frameworks resulted in us experiencing hermeneutic injustice [19, 20], where the tools to understand and communicate our experiences meaningfully were simply unavailable. As such, our experiences speak to the central importance of language in how forms of epistemic injustice are enacted [12, 19–24].

These harms were compounded by the overuse of clinical jargon—terms such as "dependent" and "care-seeking"—which we often perceived as opaque, emotionally detached, or unexplained. Acronyms, diagnostic shorthand, and medicalised terminology offered little clarity or comfort, corroborating the research literature on the negative impacts of medical jargon [120–124], which may be magnified for both patients and providers with minority language and cultural backgrounds, emphasising the importance of an intersectional, non-individualistic lens [125–127]. We found jargon and unclear terms were particularly alienating for us when we were medically compromised, overwhelmed, or struggling to process information as a result of severe malnutrition, trauma, or neurodivergence [83], reflecting experiences of healthcare communication amongst other autistic individuals documented in qualitative research [128, 129], including autistic people with EDs [130, 131].

Beyond our personal experiences, others have shown how inaccessible or bureaucratic language can support cultures of detachment in order to protect from moral injury within overstretched services [132] and how emotional connection can be displaced by a focus on procedural rationality and institutional norms [133]. This highlights how the role of language extends beyond the semantic as a relational and systemic concern. Addressing the function of language in care—how it legitimises certain forms of knowledge, excludes others, and shapes the very terms of engagement—is therefore essential in rehumanising treatment, supporting both service users and staff, and restoring dignity as a shared ethical commitment.

3.3. Implications for dignified care

The following section outlines some key practical steps to ensure that dignity is central to both the process and outcomes of care for those with LSEDs. These are summarised visually in **Figure 1** and have been identified on the basis of our own experiences; therefore, they are not exhaustive. We nonetheless hope that they assist treatment providers in creating therapeutic approaches that prioritise and balance both patient autonomy and collective responsibility, even in the most challenging of clinical contexts.

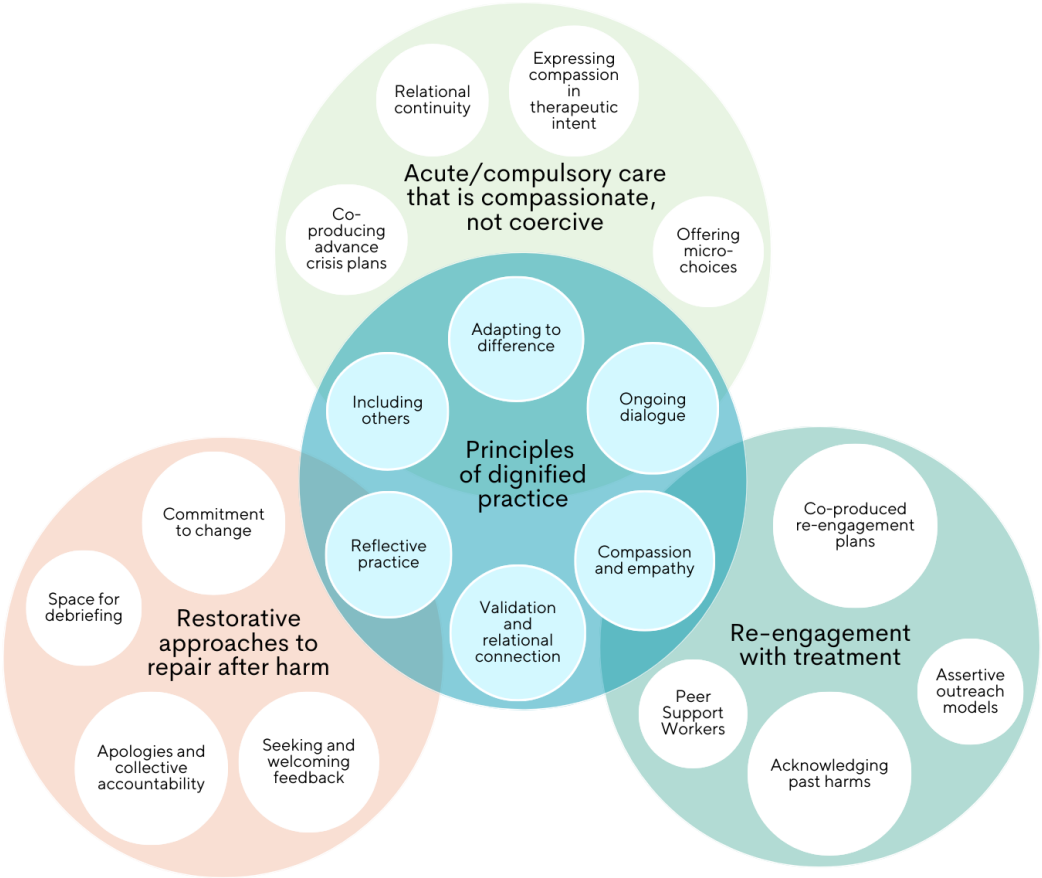

Figure 1 • Principles and practices of dignified care in longstanding and severe eating disorders.

3.3.1. Making acute and compulsory treatment compassionate, not coercive

Compulsory treatment is sometimes necessary to preserve life in LSEDs [68, 69]. However, there is a paradox—the very act of saving life can feel like a violation of personhood, leaving individuals who are treated against their will feeling disempowered and alienated from all decisions pertaining to their care [134, 135]. A recent rapid review found that there was a lack of agreement and limited clinical guidance to determine who may benefit most from compulsory treatment, highlighting the need to develop practices which minimise coercion further in order to provide more acceptable, compassionate care [136]. In circumstances where autonomy is constrained, we believe it is both desirable and often possible for patients to remain engaged as active participants in their care by having their preferences acknowledged, being involved in decision-making wherever possible, and receiving clear, compassionate explanations about their treatment as being in their best interests [137, 138].

It is also vitally important that providers recognise the community of care that patients may (or may not) be embedded into and seek to actively include any trusted caregivers and peers, as well as other clinicians [139–141]. Even when dignified treatment is not fully realised in a given moment, our own experience has been that opportunities for reflection, repair, and collective accountability after the event can help restore dignity, rebuild trust, and strengthen therapeutic relationships moving forward.

3.3.2. A shared language for ethical care

Given the power of language to shape perception, practice, and policy, we argue that the discourse surrounding LSEDs must undergo a fundamental shift, not as a cosmetic exercise but as a necessary step toward justice, dignity, and truly person-centred care. This means moving away from the examples of harmful clinical language we have discussed and towards narrative frameworks that centre lived experience, make space for contradiction and complexity, and reflect the social realities that shape suffering and care [26, 37–39].

There are many promising avenues to achieving this. For example, when used ethically and collaboratively, storytelling practices have been demonstrated to be a means of advocacy and recovery for people with EDs, challenging stigma, resisting diagnostic reductionism, and restoring voice [83, 142–144]. Innovative approaches that extend beyond the dialogue of clinical interviews or text-based narratives have also shown promise, including the use of digital media [145–148]—tools which can foster both creative expression for individuals and greater empathy and insight amongst healthcare providers [149, 150].

From the perspective of epistemic justice, promoting testimonial justice involves treating individuals with LSEDs as credible knowers of their own experience, not merely permitting them to speak but taking their accounts seriously, especially when they challenge clinical expectations or dominant narratives [21, 22]. Clinicians, researchers, and service providers can foster this by resisting dismissive or pathologising language, validating patients' interpretations of their own needs, and creating space for disagreement, ambivalence, and relational meaning [14, 151].

Achieving hermeneutic justice requires the development of shared interpretive frameworks that can make sense of experience beyond the confines of diagnosis or assumed dysfunction [152]. This means co-creating language that captures not only psychological symptoms but also ethical violations, relational harms, and systemic forms of exclusion [27–29]. Making these frameworks accessible to both professionals and those they serve is critical to building mutual understanding and accountability [30–32].

Importantly, these shifts must not be framed as individual communication challenges to be overcome by patients alone. From a communitarian perspective, ethical care is grounded not only in individual rights but in mutual responsibility, relational interdependence, and the shared moral obligations of communities and institutions [34, 35]. This demands collective responsibility, rooted in organisational culture change and supported by practical mechanisms.

For example, ensuring access to professional interpreters in mental health settings is essential for people whose first language differs from their clinicians'—a need still too often unmet in practice [153–155]. Likewise, involving caregivers as communication partners can support relational understanding, wider social involvement, and shared decision-making in contexts where individuals may struggle to articulate their needs unaided [156, 157]. Training initiatives that encourage clinicians to reduce jargon and engage in reflexive communication have shown promise in improving comprehension, therapeutic rapport, and shared decision-making [158, 159]. Furthermore, tools such as communication passports have been shown to support person-centred dialogue for autistic patients with EDs by providing clarity about individuals' preferred terms, needs, and strategies for relational safety [130].

Taken together, these examples highlight how rehumanising care through language is not merely an interpersonal task but a structural and cultural one. Building a shared language for ethical care involves shifting responsibility from individuals to systems, placing the burden of adaptation not on those most marginalised but on institutions committed to fostering relational safety, restoring trust, and upholding dignity as a collective good.

3.3.3. Emotional validation and relational safety

A central feature of compassionate compulsory treatment that illustrates the importance of language is emotional validation: the recognition and affirmation of a person's emotional experience as legitimate, intelligible, and worthy of response [160–162]. In the context of LSEDs, this becomes especially crucial, for example, when compulsory treatment occurs amid profound fear, shame, or perceived loss of control [134, 135]. Emotional validation aligns closely with trauma-informed principles, which seek to reduce harm, avoid re-traumatisation, and uphold dignity during high-risk interventions [163, 164].

Validation also carries epistemic significance. By treating emotional expression as credible and meaningful, it resists the testimonial injustice often encountered when distress is dismissed, minimised, or pathologised. From a rights-based perspective, it affirms the individual's status as a moral subject with the right to be heard and taken seriously, not merely observed or managed [165]. From a communitarian perspective, this can help foster mutual trust and moral solidarity, laying the groundwork

for a therapeutic relationship built on shared responsibility and care [166].

However, emotional validation alone is not sufficient. Relational safety is equally important for sustaining dignity throughout compulsory care and can be understood as a sense of being held in relationships that are consistent, compassionate, and trustworthy [167, 168]. Relational safety extends beyond the immediate clinician–patient dyad to include the broader care team, family members, and peer supporters, which can be an important protective factor for those with LSEDs who have experienced repeated trauma, exclusion, or iatrogenic harm [46, 169–172].

From our personal experience and available research, the following practices may help reduce fear and rebuild trust during coercive or compulsory interventions:

- Naming emotional responses with empathy: For example, being told *"I can see how frightening this is right now"* helped one of us to feel emotionally validated and better understood, even in a high-risk scenario.
- Reaffirming therapeutic intent in relational terms: Phrases like *"We are all here because we care about you and want to keep you safe"* have signalled compassionate motivation, not just clinical authority [138].
- Ensuring relational continuity: Having a familiar and trusted clinician or staff member remain present throughout the course of treatment has created a bridge of safety and connection, emphasising the importance of the continuity of care [171].
- Involving known supporters: Being able to access trusted advocates, peer workers, or family members has been a grounding influence during crises, helping to reduce a sense of isolation or betrayal [139–141, 172].

3.3.4. Safeguarding agency within limits

While compulsory treatment inevitably limits autonomy, it need not erase it. In both rights-based and communitarian ethical frameworks, preserving agency can support the rights of patients with LSEDs to participate in decisions affecting their health while sustaining the relational responsibilities that bind people within communities of care [173, 174]. Even when full autonomy is limited by risk, preserving a sense of voice, choice, and participation can reduce the harms associated with coercion and promote relational safety.

Our lived experiences affirm that agency can be sustained in small but significant ways. Despite limited evidence for how decision-making capacity operates across 'micro' and 'macro' levels [175], we have found that being offered micro-choices has helped us shape aspects of treatment in line with our personal values, preferences, and identities, even when we have had little choice about treatment as a whole. These have included being able to choose which staff member is present during interventions, selecting grounding techniques or sensory supports, and incorporating cultural, spiritual, or identity-affirming practices into care planning. For neurodivergent people and those with trauma histories, both common in LSEDs, these personalised choices can be especially vital due to cognitive, sensory, and interpersonal differences that may otherwise go unrecognised in clinical care [90, 91, 95].

These treatment approaches reflect the principle of the least restrictive practice, defined as the imposition of the minimum necessary limitations on liberty required to ensure safety and therapeutic benefit [176]. However, what constitutes the "least restrictive alternative" is often subjective and contested, particularly in the treatment of LSEDs, where life-saving interventions may be resisted, and the boundary between strong persuasion and coercion can blur [135, 136]. For instance, Minuti et al. [177] highlight how clinicians' assessments of capacity and thresholds for intervention vary widely between and within countries, with differing views on whether patients with AN are capable of autonomous decision-making. This highlights how clinical judgements are shaped not only by illness severity but by wider cultural, legal, and systemic norms that influence how risk and autonomy are interpreted.

Despite these challenges, there is growing evidence to support practices that reduce the reliance on coercion and uphold dignity in treatment for LSEDs. Drawing on multi-informant qualitative interviews, Fuller et al. [178] found that individualised care, open communication, and trusting staff–patient relationships were central to reducing the incidence and harms of nasogastric feeding under physical restraint. In their study, care that acknowledged the unique needs of each person was perceived as more humane, less traumatising, and ultimately more effective than following rigid protocols.

Importantly, while relational dynamics are vital, there are also structured opportunities for safeguarding agency within compulsory care. One example is the use of advance care plans or crisis plans—preferably co-produced outside acute settings, often with caregivers or peer supporters, and regularly reviewed [179, 180]. These can allow individuals to express treatment preferences and preserve boundaries in times of crisis, even when their mental state and decision-making capacity fluctuate, as is known to be the case in LSEDs [181–183]. When used well, such plans reflect epistemic justice by recognising the person's knowledge of their needs, values, and social world as credible and relevant in clinical decision-making. However, searching the literature gave rise to little evidence for the effective implementation of these tools in the context of LSEDs, mirroring our personal experiences and suggesting a key gap for future research.

3.3.5. Restorative approaches to repair after harm

As illustrated, experiences of coercion, neglect, or exclusion can lead to individuals with LSEDs experiencing iatrogenic harm—that is, harm arising as a consequence of the treatment process itself [46, 171, 184]. Importantly, such harm is not only the result of extreme interventions such as restraint or forced feeding but also more diffuse experiences of invalidation, disconnection, or a lack of voice within care systems, resulting in avoidable social and psychological injuries for patients and their families [185–187]. This can, in turn, erode trust in services and contribute to disengagement from future ED care [169, 170, 173].

The psychological framework of Self-Determination Theory (SDT) offers a lens for understanding how and why such harm occurs [188]. SDT conceptualises psychological well-being as dependent on the fulfilment of autonomy (a sense of control and volition), competence (feeling effective and respected), and relatedness (feeling connected and valued by others), and research in inpatient mental health settings suggests that when these needs

are undermined, treatment is more likely to be experienced as harmful or traumatic [189, 190].

Where such harm has occurred, restorative approaches may offer a structured means of repairing the psychological and relational ruptures that result when core needs for autonomy, competence, and relatedness are undermined. Rooted in justice-based frameworks, restorative practices prioritise emotionally honest, facilitated dialogue in which those affected can acknowledge harm, share perspectives, and collaboratively identify changes to prevent recurrence [190]. Rather than centring blame, they emphasise emotional recognition, mutual learning, and shared accountability and have been increasingly proposed as alternatives or complements to formal complaint mechanisms in mental health settings, particularly when harm has arisen from systemic failures rather than individual misconduct [187, 191, 192].

An illustration of principles is provided in Collins' autobiographical account of her 20-year journey through eating disorder services. Her experience involved over 30 hospital admissions and repeated coercion, including forced feeding and long periods of involuntary treatment [56]. Collins describes how she interpreted being labelled a "SEED patient" as a way for services to justify "giving up" on her. It was only when care became relational, trauma-informed, and creatively co-produced—through humanising therapeutic encounters and the incorporation of personal interests such as painting within her treatment plan—that Collins began to experience meaningful recovery. Her account is evidence of a recovery that was not achieved through greater adherence to standardised protocols or stricter control but through relational repair, validation, and personalised support that treated her as a full person.

3.4. Structural considerations

There are significant structural barriers that currently limit the provision of dignified, sustained care for individuals with LSEDs. These include the absence of long-term treatment frameworks, regional variation in access to specialist support, exclusion from services due to perceived treatment resistance, and a general lack of resources and training [8–10, 52–54]. As noted, fragmentation across medical, psychiatric, and psychosocial care domains compounds these issues further, often leaving patients to navigate systems that do not adequately recognise their complex needs [130–132].

Reorienting care models, therefore, requires not only therapeutic improvements but also broader structural transformation. These structural considerations underpin the three core priorities emerging from our evidence synthesis, namely: (a) re-medicalising care in a way that respects agency and complexity, (b) embedding dignity into service design, and (c) supporting epistemic justice via co-production. The following sections explore these priorities in more detail.

3.4.1. Re-medicalising longstanding and severe eating disorders without reducing agency

The findings of this paper highlight how individuals with LSEDs often experience exclusion from care due to diagnostic ambiguity, assumptions of non-recoverability, and a lack of sustained medical engagement. In response, re-medicalisation offers a pathway to redress these harms by reaffirming the clinical seriousness of LSEDs and re-establishing access to care grounded in medical need rather than perceived futility. This does not imply a return to narrow biomedical models but a deliberate effort to re-centre the body within ethical and interdisciplinary care [99, 112].

Re-medicalisation involves recognising the ongoing medical risks associated with LSEDs and consistently implementing evidence-based criteria for treatment escalation to ensure that decisions are driven by clinical need, not assumptions about chronicity [3]. Equally important is the integration of nutritional rehabilitation as an essential component within comprehensive recovery plans, rather than as an isolated metric [42, 106]. Similarly, interdisciplinary collaboration, encompassing medical, psychiatric, and lived-experience expertise, is essential to addressing the multifaceted and frequently comorbid nature of LSEDs [106, 112, 193, 194].

This re-medicalisation must also be viewed through an ethico-legal lens, recognising the duty of care that healthcare providers have to individuals with EDs. This includes the duty to provide reasonable adjustments, which is particularly relevant in jurisdictions such as the UK under the Equality Act 2010, ensuring that those with LSEDs are not disadvantaged in accessing appropriate care due to their specific needs [195]. Given the substantial health inequalities in LSED care, particularly for those from marginalised communities, the right to health and life must be upheld by ensuring that treatment is both evidence-based and equitably accessible. While the specifics of legal protections and healthcare obligations vary by jurisdiction, these principles hold global relevance.

3.4.2. Embedding dignity in service design

A lasting transformation in LSED care requires that dignity be embedded not only within therapeutic encounters but across service design, governance, and resource allocation. This means investing in sustainable, person-centred service models that are equipped to address the many structural and intersecting barriers we have discussed that limit access for people with LSEDs. Adequate funding for care pathways that provide suitably intensive treatment and continuity of care is essential [1, 49, 50], as is the implementation of national strategies and evidence-based guidelines that support the dignity-oriented principles we have outlined. Dignity-centred care cannot be implemented sustainably without resourcing the people expected to deliver it, either: significant investment in workforce development is required to address the high rates of staff burnout and moral distress that can erode the ability to deliver compassionate, reflective care [54, 132, 196, 197].

In addition to improving the resourcing and quality of care, the way treatment is organised and accessed for LSEDs must also recognise that re-engagement often occurs against a backdrop of repeated and sometimes distressing experiences of care, such as those we have discussed. High rates of treatment non-response, premature discharge, and disengagement reflect systemic failures to meet the needs of this population [198–200]. Re-engagement must contend with the legacy of harm and disempowerment that many individuals with LSEDs carry. In our own experiences, we have sometimes been pushed towards starting change-based therapeutic interventions in order to meet waiting time metrics that define the quality of service provision, giving little space for past harms to be redressed and a trusting therapeutic alliance to be established. As such, structural changes to how treatment

initiation is defined and measured may be needed for those with LSEDs who may need more time and resources when re-entering care. Additionally, assertive outreach models, while underused in ED services, may help shift the burden of engagement away from individuals whose ambivalence reflects prior systemic failure [201].

3.4.3. Co-producing knowledge, treatment, and justice

In order to advance epistemic justice, treatment guidelines, care pathways, and service principles must be co-produced with individuals with lived experience of LSEDs and their carers, supporters, and wider communities, in order to ensure that these frameworks reflect the complex realities and aspirations of those most affected [30–32, 53]. This includes actively centring diverse forms of knowledge and experience—ensuring representation across axes of marginalisation, including race, class, gender, disability, and geography—particularly given the systemic inequities in both access to care and voice within service design processes [84, 202–208]. If not carefully undertaken, co-production may replicate existing power imbalances, with professional or academic voices dominating, and patient knowledge treated as anecdotal or supplementary [209, 210]. Similarly, it may also give rise to excess emotional labour or be experienced as re-traumatising [211, 212]. As such, meaningful co-production must therefore be relationally attuned and structurally supported [213, 214].

Encouragingly, emerging models of the best practice in co-production are beginning to reshape mental health research and service development. River et al. [215] describe a co-produced training intervention developed by individuals with lived experience, clinicians, and researchers, highlighting the value of shared authorship, relationship-building, and iterative feedback in fostering mutual understanding and culture change. Others have produced models which integrate trauma-informed facilitation to ensure the involvement of vulnerable groups is accessible and materially influential rather than symbolic [216]. In the context of EDs, co-production methods have been adopted across policy, research, and the design and implementation of clinical interventions [217–219], with studies working with autistic patients providing examples of how involvement can be made more accessible and inclusive [220, 221]. While the field of co-production is still emerging, these examples offer vital starting points for embedding dignity into system design.

Finally, this commitment to equity and epistemic justice must also extend to research. Too often, the knowledge base that informs treatment guidelines and service design is shaped by unrepresentative samples, excluding those who are most marginalised, least engaged, or most harmed by services [75, 76]. Correcting these imbalances requires intentional recruitment strategies, participatory methodologies, and critical reflexivity about whose voices are amplified, whose are excluded, and why [222].

4. Conclusions

A synthesis of the existing research literature and our lived experiences provides evidence for the treatment of LSEDs too often being characterised by the denial of dignity. This is driven by many factors, including systemic demedicalisation of illness, damaging narratives of chronicity, and coercive frameworks that marginalise patient agency, amongst others. Existing frameworks often fail to meet the complex needs of those affected by LSEDs in ways that perpetuate cycles of suffering and exclusion. Dignity, when viewed through a rights-based lens, is not a privilege but an inalienable right that should underpin every aspect of care. The treatment of LSEDs must recognise not only the individual's autonomy and agency but also the interconnectedness of individuals within their communities and society.

By integrating lived experience, trauma-informed care, and co-productive practices, alongside fostering interdisciplinary collaboration, we have the opportunity to reimagine care in a way that honours these multiple conceptualisations of dignity. Such a shift would not only restore dignity in its most individual and collective senses but also create meaningful pathways toward recovery—pathways grounded in respect for personal rights, community values, and epistemic justice. Through these transformative practices, we can create a future where those with LSEDs are recognised and supported in their full humanity and their journey toward healing is one that respects both their individual needs and their place within society.

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